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103d Congress

United States House of Representatives
Committee on Small Business

Subcommittee on Regulation,
Business Opportunities, and Technology

B-363 Rayburn House Office Building
Washington, DC 20515-6318

March 22, 1993

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TO: Ron Wyden, Chairman, Subcommittee on Regulation, Business
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FROM: Subcommittee Staff

SUBJECT: Residential Programs for the Mentally Retarded:

Out of Sight. Out of Mind?

Poor Quality Care, Waste and Theft of Millions in Public
Reimbursement; Dangerously Inadequate Oversight by
Federal, State and Local Authorities

INTRODUCTION

In the last session of Congress, the subcommittee examined a number of emerging small business trends in the healthcare industry. Increasing healthcare costs as well as changes in practice standards and standards for acceptable providers have given birth to a myriad of non-traditional healthcare business opportunities. Among those examined by the subcommittee has been the emerging field of ambulatory surgical practices, head-injury rehabilitation facilities and clinics providing alternative and non-traditional health treatments.

An area of increasing healthcare quality and cost - containment concern, however, is the long-term treatment of the mentally retarded and developmentally disabled. Increasingly, millions of Americans with these life-long handicaps are at risk from poor quality care, questionable and even criminal management practices by service providers, and lackluster monitoring by public health and welfare agencies.

This is a service sector dominated by small business providers, and which generates in excess of \$11 billion per year in revenues, much of it reimbursed through state and federal health insurance programs.

Subcommittee staff has conducted a year-long investigation of providers of assisted and independent living arrangements for the mentally retarded. The result indicates that growth in this industry has out-stripped the ability of many state agencies to adequately oversee conditions in these facilities.

A disturbing pattern of abuse, neglect and fiscal mismanagement has emerged.

Central to this issue is how to best protect the health and welfare of citizens who are in the public trust — in other words, persons of diminished intellectual capacity who are unable to effectively protect themselves when selecting or receiving healthcare services.

There are over seven million retarded persons currently living in the U.S. Estimates of the 1988 average daily population of Mentally Retarded/Developmentally Disabled (MR/DD) individuals living in residential facilities, foster homes, psychiatric facilities and nursing and personal care homes nationwide range from 268,771 to approximately 330,000. Because the mentally retarded often cannot speak in their own interest, there is a compelling need for government oversight.

Federal Medicaid funding for just one sub-set of the industry — mid-sized, intermediate care facilities, rose from \$573 million in 1977. to \$2.4 billion in 1988.

Increasingly, however, privately operated homes for the mentally retarded and developmentally disabled fall through the regulatory cracks.

Annually, the federal government spends billions of dollars on care for the mentally retarded and developmentally disabled, mostly through small business operators in the field. Of the \$11.7 billion generated in residential treatment of the mentally and developmentally disabled in 1988, approximately \$4 billion came from Medicaid, \$3.6 billion came from the federal Title XIX program, and \$2.1 billion came from Supplementary Security Insurance.

WHAT STAFF HAS FOUND:

- * Some providers operating networks of homes continually violate Medicaid regulations and public health codes. Problems include: poorly trained and abusive staff, inadequate oversight of medication, poor food, dangerous sanitary conditions, lax accounting and record keeping.
- * Both for-profit and non-profit providers who have incestuous relationships with subsidiary, for-profit corporations to lease-back housing, provide employment and physical therapies, and consulting services. These relationships appear to be designed to maximize profitability of these ventures for managers, yet they clearly constitute conflicts of interest and, in some cases, violations of law.

For example, the State of Massachusetts estimates that abuses in that state could be as high as \$50 Million over the last four years.

- * Homes and providers across the country have been cited for pages of health and safety code violations. Yet some states have not closed down a single home for poor conditions or failures to provide contracted services. For example, a Michigan operator obtained four licenses to run small group living facilities and then pooled his clients into a single, more profitable facility that the state was finally forced to close because of adverse health conditions. This closure, however, occurred only after years of reported patient and financial abuse.
- * Regulators are unsure of which agency wields ultimate authority in a state for MR/DD programming, and there is significant confusion regarding jurisdiction. This leads to poor oversight, and the continuation of unhealthy, financially abusive and even dangerous conditions at some homes dependent on significant public support. Federal auditors, for example, often have little knowledge of how monies flow through state agencies to intended beneficiaries.
- * Employees at small, community based facilities are often under-trained, poorly paid and inadequately screened. As one New York state official put it: "some consumers leave institutional programs where staff have received 100 hours of training and move to homes where staff do not even know first aid."
- * Home residents have been the victims of physical and emotional abuse and neglect. Marlene Carson, an Oregon mother, complained to the subcommittee that: "they don't tell guardians anything." Her son — a resident of a supervised small group living apartment complex — had wandered away from
 - the facility, sometimes missing for days at a time, before she was notified that he was gone.

According to a recent Miami Herald article on problems in MR/DD programming: "For the lucky, the new 'system' works. They have found or been placed in group homes that work as homes, that offer clean shelter and caring hands. For the others, though, the snake pit has only broken into nests that are out of sight and out of mind."

The court-ordered rush during the last ten years to move mentally retarded and developmentally disabled persons out of oppressive, large, state-run facilities has resulted in the creation of myriad of small, privately operated "homes." These small business ventures easily slip through poor or non-existent federal, state and local quality assurance efforts.

The subcommittee has scheduled a hearing to examine these issues, time and place as follows:

Time: 9:30 a.m. Date:
Monday, March 29, 1993
Place: Room 2359 Rayburn House Office Building
Washington, D.C.

I. PATTERNS OF ABUSE

In state after state, subcommittee staff learned of charges of physical abuse, neglect, and potential profiteering.

Typical examples of abuse, neglect and profiteering include:

CONNECTICUT:

Connecticut Community Services (CCS), a West Hartford, nonprofit corporation, received \$3.4 million from the state last year to operate nine group homes for retarded adults. State auditors found that CCS owes the state \$425,000 for improper or unsupported billings over a period of three years. In addition, the company owes the state another \$526,000 for its failure to return double payments made by state agencies over the past few years.

The founders and owners of Charter Oak, another group home program, opened homes in Connecticut after having just left a Salem, N.H. group home in bankruptcy. It took less than two years for their Connecticut homes to reach the same predicament. Inspection reports of homes cited low food supplies, staff shortages, lack of programs for residents, filthy clothing and evidence of neglect, such as men who had gone unshaven and women who had developed yeast infections. Inspections also found that untrained staff members were giving prescription medication to residents. Professional medical services were considered inadequate and blamed for a 30-year-old retarded man's accidental overdose of lithium and other behavior-modifying medications in January, 1989. The man was hospitalized. The company owes the IRS more than \$100,000 and owes hundreds of thousands more to a firm that renovates houses and rents them to group-home operators.

MASSACHUSETTS

The Center for Humanistic Change in Springfield directed \$1 million of its state contract money for-twenty group homes to other businesses Center owners controlled. In several cases the Center, which is private and nonprofit, paid inflated prices to rent buildings owned by the Center's three founders, or paid administrative service fees to a company also owned by the founders. On disclosure forms required to be filed with the state, the Center apparently violated state law by concealing the fact that its administrator also owned a realty trust and rental company from 'which the Center subcontracted services. State officials terminated the Center's \$5 million per year contract.

Massachusetts Deputy Auditor Robert Powliati³ told subcommittee staff that fraud and misappropriation of state funds directed to small group home operations in the state "conservatively" run as high as \$10 million per year and may be as much as \$50 million over the last four years.

MICHIGAN;

In Imlay City, Brenda Berger, a 30-year-old mentally ill woman died after the state Department of Social Services had warned her group home for months that it was improperly administering Berger's drugs. Berger's death also occurred two months after the department notified the home its license was being revoked for serious care violations. Forensic experts were unable to identify Berger's cause of death.

NEW YORK:

The Hi-Li Manor Home was cited during 1990 as one of the 14 worst adult group homes in the state by the State Commission on Quality of Care for the Mentally Disabled. Instead of upgrading care, the managers funneled \$4 million of public funds, including Medicaid dollars, into investments, interest-free loans to themselves, excessive salaries for themselves and relatives, car purchases, tuition payments for relatives and insurance payments on homes, and jewelry and furs, according to the state oversight agency.

IV. INADEQUATE LIVING CONDITIONS AND ABUSE OF RESIDENTS

Federal law requires the placement of retarded people in the least restrictive environment that is consistent with their physical and mental needs. The Health Care Financing Administration "has enforcement authority over homes receiving Medicaid. Nevertheless, sporadic incidents of inhumane treatment are a recurrent problem. For example:

- Five homes in Bakersfield and Lamont, California, were closed in April 1992 for alleged neglect and endangerment of adult, mentally retarded clients. One staff member served six months in jail for sexual battery. Another staff member is accused of using restraint methods so violent that he broke a client's arm. Even the home proprietor has been accused of punching a client in the face.
- In Michigan, state mental health officials investigated the case of a group home client who almost died as a result of a drug overdose. State reports of the investigation reveal that cockroaches were crawling across the pages of the medical log reviewed by state investigators and that resident medicine was generally kept in unmarked brown paper bags. The home had been cited repeatedly since 1985 for violations, yet remained in operation.

Although many, if not most homes for the mentally retarded and developmentally disabled are clean, safe and well-managed facilities, others are cause for grave concern. In the words of Jay Klein of the Institute for Disabilities at the University of New Hampshire:

"The system we've set-up is crazy ... what we are building is disability ghettos."

V. DENIALS, INTIMIDATION AND COVER-UPS

Parents and guardians complain that they are routinely denied access to their children's medical records and other critical information. No legitimate business reasons are offered for such secrecy.

- At one residence, staff members were required to sign a form that explicitly threatened termination for any employee who spoke out publicly about conditions in the home.

Home operators have also sought to intimidate the retarded residents in their care:

At a home in Michigan, residents were beaten by staff for talking to reporters and government investigators. The retarded residents had complained about being forced into sexual relations with the home manager.

VI. INADEQUATE QUALITY ASSURANCE AND FACILITY OVERSIGHT

Subcommittee staff have identified a number of troubling loopholes in state and federal regulations pertaining to quality care for the mentally retarded and developmentally disabled, and numerous flaws in government enforcement measures. Often, facility operators are inordinately preoccupied with passing irregular and periodic inspections rather than striving for a high level of care. Although indications are that most homes provide quality care in an efficient, caring and lawful manner, too many providers have routinely taken advantage of complex rules and regulations for personal gain.

Specific deficiencies in the way the system is organized and in the way it operates almost invite companies to thwart the rules:

Deficiency #1 Many states perform inspections infrequently and usually give prior notice.

Not surprisingly, homes pass inspection by making special preparations before scheduled on-site visits. But performance and a home's appearance during an inspection may indicate little about staff conduct during the rest of the year.

The system, in short, as Jay Klein, Professor at the University of New Hampshire and expert on MR/DD housing, told the subcommittee, is one of "'Dump and Hope'... dump the people in a home and hope nothing bad happens".

Deficiency 12: Staffing levels on inspection and auditing teams are too low to perform comprehensive and frequent examinations.

Unscrupulous providers recognize blatant abusers will be targeted. Merely by keeping a low profile, careful scrutiny. Further, in -- the first line of protection too many cases and unable to services provided to individuals

that only the most by state agencies. Home operators can avoid states case managers are over-burdened with effectively oversee the R/DD clients.

As was reported in a 1991 study Minnesota's Center for Residential and Community Services suggests almost exclusive dependency for services on provider self-reporting of recipient needs and program deficiencies, or on the complaints of recipients, family members or interested others."

by the University of Minnesota's Center for Residential and Community Services, in some states "so infrequent as to make quality monitoring needs and program

University of Minnesota Professor K. Charlie Lakin told the subcommittee that when it comes to quality assurance, inspectors and case workers may "understand their checklists well, but understand the quality of life for clients hardly at all."

Deficiency #3: Agency oversight teams frequently judge contractors solely on their record keeping ability.

Home operators may slavishly follow paperwork requirements, yet provide only the bare minimum of required care and services. Innovations -- developing programs outside the straight and narrow -- is discouraged. Furthermore, concerned employees and parents charge that records are easily altered and manipulated to satisfy regulatory requirements.

Federal support for MR/DD programming comes through Medicaid funding overseen by the Health Care Financing Administration (HCFA). However, because states operate MR/DD programming under a Medicaid waiver, HCFA's review procedures consist solely of auditing financial reports, examining receipts, and evaluating processing and compiling procedures.

In the best of circumstances, the Medicaid waiver enables states to tailor residential programming to individual needs and state conditions. In the worst cases, federal dollars wind-up subsidizing questionable programs and providers with little or no direct oversight.

Deficiency #4: Certification requirements, background checks and investigation of qualifications are often procedural and cursory.

In many states, virtually anyone can open a home. Little regard is given to an owner's track record in other states. Owners need not have any experience with the special needs of the mentally retarded community.

Deficiency #5: Procedures for revocation of a license are not credible.

Providers operating multiple homes have tremendous clout in many states. Usually, if a home fails the residents have nowhere else to live. States cannot credibly threaten to shut down a home unless appropriate alternative living arrangements exist.

Nancy Rosenau, an official at the Macomb/Oakland Regional Center outside Detroit, Michigan, explained the danger: "The key is to not have any one provider larger than we can put out of business – we don't want to be at their mercy¹¹."

Competition among service providers – a key selling point for privatization of residential services – gets mere lip service in many areas. States usually roll-over expired contracts, rather than opening up the process to competitive bidding. State reluctance to move against questionable providers was highlighted in the University of Minnesota study which found that about half the states responding to its survey reported "rarely or never penalizing providers for deficiencies noted in the quality of their services..."

VII. WASTE. FRAUD AND ABUSE IS GROWING

Predictably, some unscrupulous companies have taken advantage of complex regulations and oversight deficiencies. Some representative examples:

A group of businessmen in Massachusetts illegally sold group homes to a business they owned, at inflated prices. They also hid doing business with a related party, contrary to Massachusetts law. They pleaded guilty to cheating the state of \$500,000, which paid for a Florida condominium.

Connecticut paid out \$230 million for care for the retarded without auditing a single operator. When the state finally conducted a limited review of two providers, the state found that one provider, Connecticut Community Services, Inc. (CCS) spent \$425,000 for improper or unsupported billings over a period of three years.

In addition, the investigation discovered that CCS owes the state another \$526,000 for its failure to return double payments made by state agencies over the past few years. Forced by court order to remove individuals from state-operated hospitals, Connecticut rapidly contracted with almost any business willing to provide immediate services.

State officials concede that they made mistakes, but they contend that most of the expenditures were technically legal. Some home operators realized that they could buy "gold -plated" structures from related parties — really from themselves — and charge the state exorbitant prices. The state has since tightened its regulations, but the damage has been done.

VIII. UNDER-TRAINED AND POORLY COMPENSATED STAFF

Virtually all homes in the community employ personnel who have little experience working with mentally retarded or developmentally disabled individuals . To satisfy training requirements, many providers give employees only the most basic healthcare training — for example, a two-week crash courses in first aid may be the only specialized training that an employee will have.

Poor staff compensation is virtually universal for those paid to care for our nation's most vulnerable citizens. The 1992 mean starting wage for direct care workers in private community facilities nationwide was approximately three percent above the poverty level for a family of three. More than 50 percent of private community facilities report starting wages for full -time workers that are below the poverty level for a family of three.

- * Seven state-specific studies conducted between 1986 and 1989 indicated that on average the wages paid by community facilities were 54 percent less than institutional wages. Average institutional wages are \$8.72 per hour, while private community facility wages average only \$5.97 per hour.
- * Starting wages in private community facilities can be as low as \$5.22 per hour.

Across the board, wages have failed to keep pace with inflation over the past de cade.

Community facilities also offer substantially fewer employee benefits than their institutional counterparts. For example:

- * A significantly lower percentage of community facility employers offered dental, retirement, child care, and tuition assistance benefits than institutional employers in 1992.
- * A 1988 Maryland study found that institutional benefits averaged 40 percent of wages, while community facility benefits averaged only 16 percent of wage³.

Not surprisingly, staff turnover is a major problem. Furthermore, experts link dissatisfaction over low wages with a tendency to abuse or neglect the clients. A 1980 survey of more than 2000 facilities found that the most frequent difficulty reported was recruitment, retention, and development of staff (85 percent of reporting facilities).- Turnover was reported as an even more serious problem than obtaining adequate funding (65 percent) .

Employee turnover was almost three times as much as institutional turnover in 1992 - 70.7 percent annual turnover for private community facilities compared with 24.8 percent for institutions. In seven states, the turnover rate was over five times higher in private community facilities than in institutions. The turnover rate for community facilities increased by more than 25.percent over the past decade.

The national mean length of service for full-time staff in institutions was 50.3 months, compared to only 14.7 months in private community facilities. More than half (55.9 percent) of the direct care staff separating in private community facilities leaves before completing one year on the job compared to less than one third (30.7 percent) of the workers in institutions.

In sum, low wages and poor training have become the hallmark of many private facility staffs.

"They're hiring people off the street for \$5 or \$6 an hour to care for patients who have extremely complicated seizure disorders, feeding tubes, all kind of problems" Dr. Cindy Ochs of Livonia, who cares for mentally retarded residents at about 40 Metro Detroit homes told the Detroit Free Press in a 1992 article on problems with community living situations in Michigan.

When these factors combine, woefully inadequate care can result:

Subcommittee staff talked with numerous current and former employees at care facilities who freely admitted unprofessional and potentially dangerous practices by their colleagues.

For example, former employees of one facility reported that prescribed medications for residents are routinely discarded. Later, current employees reported that the medicine was administered.

Many of the problems arising in these facilities do not surprise the experts who have assessed the relationship between salaries and benefits, and the quality of healthcare. According to Dr. Dale Mitchell, Professor of Public Health at the University of Illinois, that "the MR/DD community facilities compete with McDonald's in the labor market for employees."

IX. FEDERAL AND STATE FUNDING FOR HOUSING THE MENTALLY RETARDED AND DEVELOPMENTALLY DISABLED

Annually, the federal -and state governments spend billions of dollars in an intricate system of care for the mentally retarded. Total MR/DD spending, both federal and state, increased from \$3.5 billion in 1977 to \$11.7 billion in 1988, representing a 72 percent increase in real terms and a 234 percent increase in nominal terms. Spending for facilities with 15 or less residents increased from \$879 million in 1977 to \$5.6 billion in 1988, representing a 225 percent growth in real terms and a 541 percent growth in nominal terms.

It is difficult to generalize people's specific needs, because impairments range from very slight to profound. Many mentally retarded and developmentally disabled individuals are more than capable of living on their own, with little or no extraordinary guidance. Many others, though, have a mental capacity and physical debilities which demand supervision and a special level of care. A significant number of people require assistance in daily tasks of living, like bathing, dressing, and preparation of meals. More than anything else, most of these people need a caring environment of well-trained professionals.

The services that are provided to people with mental retardation or developmental disabilities are spread out among several programs. Initially, most lived in hospitals and other large institutions, often placed indiscriminately with the mentally ill. Following the Willowbrook scandal in the late 1960s, governments transferred many people to community placements. Many now live in intermediate care facilities for the mentally retarded, generally large centers with training facilities and physical and mental therapy. More and more, states are turning to home and community-based services, which usually group five or fewer residents into an apartment -like setting to reduce costs.

Other individuals live in less formal settings; homes with family, nursing homes, or board-and-care facilities.

Over the past 15 years, the number of residents in small facilities increased significantly while the number of institutional residents substantially declined. In 1977, there were 40,424 MR/DDs in facilities with 15 or fewer residents. By 1982, this number increased to 63,703 MR/DDs. By 1988, there were 131,161 MR/DDs living in facilities with 15 or fewer residents. Meanwhile, there were 207,356 MR/DDs living in facilities with more than 15 residents in 1977. By 1982, this number declined to 179,986. By 1988, there were only 137,610 MR/DDs living in facilities with more than 15 residents. One impetus for the decrease in institutional residents is rising costs. Institutional average daily costs rose from \$87 per day per resident in 1977 (in 1988 adjusted dollars) to \$154 per day per resident in 1988. The average daily cost of care rose to \$196.33 per day in 1990. Current average institutional daily costs are estimated to be well over \$200 per day.

Between 1977 and 1988, mentally retarded or developmentally disabled persons in semi-individual/supplemented living programs increased from 1,993 to 17,646. MR/DDs in specialized MR/DD foster care increased from 15,435 to 23,568. MR/DDs in generic foster care decreased from 21,410 to 13,981. MR/DDs in nursing homes increased slightly from 42,242 to 45,843. Also, MR/DDs in state mental institutions decreased from 15,524 to 1,970.

Funding and responsibility for the housing of the mentally retarded population is diffused among several agencies at the federal, state, and county levels, and shared with numerous advocacy groups and private accreditation councils. Medicaid now covers individuals in intermediate care facilities, as well as those placed in the community. Home and community-based services, however, are administered almost entirely by the states, under a Medicaid waiver. Other funding comes from Supplemental Security Insurance (SSI), from food stamps, and from various state agencies.

This diffusion of financing sources contributes to the lack of oversight and quality. As a result, regulators often don't know who has the ultimate oversight authority, and federal auditors may have little knowledge of how monies flow through the states to the intended beneficiaries. According to state and federal sources, some residential directors may not even be aware that their funding comes from the federal government.

As previously mentioned, total MR/DD spending, both federal and state, increased from \$3.5 billion in 1977 to \$11.7 billion in 1988, representing a 72 percent increase in real terms and a 234 percent increase in nominal terms. Total public funding for facilities with 15 or less residents was \$5.6 billion in 1988, \$1.4 billion coming from the federal government and \$4.2 billion from the states.

The Medicaid budget has increased from \$32.7 billion in 1989 to an estimated \$81.5 billion in 1993. The federal government funds between 50 percent and 78 percent of Medicaid costs. Approximately 10 percent of the states' tax revenues was consumed by Medicaid in 1990. One report estimated that approximately 1.2 million mentally retarded or developmentally disabled individuals received some type of Medicaid funded service in 1987. Another report estimated that nearly \$4 billion in federal Medicaid funding went to MR/DDs in 1988. Approximately 75 percent of federal Medicaid funds went to intermediate care facilities for the mentally retarded (ICF/MRs) with the remainder going to small residential facilities and community services for persons living with families.

** Total Title XIX expenditures for the mentally retarded or developmentally disabled increased from \$616 million in 1977 to \$3.6 billion in 1988.

** Title XIX Funding for large public ICF/MRs increased from \$573 million in 1977 to \$2.4 billion in 1988.

** Funding of large private ICF/MRs increased from \$33 million in 1977 to \$451 million in 1988.

** Funding for small private ICF/MRs increased from \$9 million in 1977 to \$443 million in 1988.

Federal Supplemental Security Insurance payments to the mentally retarded or developmentally disabled totaled \$2.1 billion in 1988, which represented 23 percent of total federal SSI payments to blind and disabled payments. There were approximately 720,816 MR/DD recipients of federal SSI funds. State SSI payments to MR/DD's totaled \$316 million in 1988, which represented 16 percent of total state SSI payments. There were approximately 239,077 MR/DD recipients of state SSI funds.

Compounding the fiscal quagmire, multi-state, multi-home chains have entered the marketplace. "Mom and pop" foster homes are being rapidly replaced by large corporations. The subcommittee has discovered that some ostensibly nonprofit organizations operate for-profit subsidiaries; the incestuous business relationship between for-profit and nonprofit entities suggests that Medicaid may be paying less for the direct care of the residents and more for organization, accounting, and executive salaries.

The states claim, with considerable justification, that they lack the resources and authority to audit multi-state providers. State governments are primarily responsible for the care that is given within their borders. Even if every state carried out this duty to perfection, the labyrinthine organization of some of these corporations could escape effective audit.

Clearly, the federal government has a role to play in ensuring the financial propriety of companies that receive federal funds. But, according to officials in the Health Care Financing Administration, federal policy grants the states almost complete enforcement of Medicaid regulations regarding the mentally retarded and developmentally disabled. Even though many states acknowledge they lack the means to trace the background of prospective entrants into the field, HCFA gives the states little guidance.

X. STATES CAUGHT IN THE CROSSFIRE

The Medicaid waiver program assigns states the primary duty to police the system. Theoretically, the states have significant incentives to carry out this task. States are responsible for between 22 percent and 50 percent of program costs.

The facts, however, taint this scenario. When the states are confronted with aggressive, well-organized corporate octopi, they often lack the resources or will to conduct careful review. In Michigan, for example, the number of adult foster care homes grew by 37 percent in the last decade, yet no new inspectors were hired.

In an era of scarce resources, state Medicaid Fraud Control Units, training and auditing programs are tempting budget-cutting targets even though they save more money in the long run. Forty-one states have Medicaid fraud units established to investigate questionable activities. However, commitment to these efforts vary by state. Some states, like New York, have made a major commitment of staff and other resources, winning significant victories. Other states with small staffs appear to only be going through the motions. More importantly, as with all too many healthcare frauds, corporations and questionable providers can avoid scrutiny by crossing state lines.

Even within the states, a chaotic and fractured bureaucracy paralyzes effective state action. HCFA regulations dictate that federal monies flow through a single state agency. But in reality, the financial accountability may be broken up between several departments.

HCFA officials complained to subcommittee staff that the maze of state agencies continually thwarts efforts to investigate payments made to homes for the mentally retarded.

Gerry Provencal, the Director of the Macomb/Oakland Center in Michigan, said:

"States that have poor community-based operations are often characterized by a maddening lack of clarity in their interagency division of responsibilities, beginning with, 'Who has ultimate statutory responsibility for the consumer's welfare?' to understanding which agency has the duty to ensure that the plumbing works, the staff are trained, and the provider is not an absentee.

"There is question to doubt responsibility, authority, and initiative."

RECOMMENDATIONS

Some parents, concerned by abuses within the developing care industry and a perceived lack of responsiveness on the part of state agencies, argue that a return to housing the most difficult mentally retarded or developmentally disabled clients in large, state institutions has merit. These critics argue that in the large institutions — even at their worst — services and programming are centralized and the size of the facility militates against the most overt forms of physical and emotional abuse. These parents and guardians argue that all too many states have used the closing of large state facilities to cut costs at the expense of care quality for a vulnerable client population.

However, small business entrepreneurs in many states have shown that these services can be provided effectively in much smaller facilities. Neglect and abuse cited as the cause in the closure of many large state operated facilities suggests that the real issue may be the ability of states to provide a wide variety of care and housing options rather than relying too heavily on one system or the other.

MR/DD populations are not monolithic, their service needs and abilities vary greatly, and the significant federal contribution to paying for KR/DD services should be used to leverage and enhance models and programs that work, and discourage waste, fraud and abuse in programs that fail.

Authorities should require a standard for measuring real quality assurance rather than finance the exchange of one questionable system for another.

There are clearly several areas where federal policy and contributions to state MR/DD program funding could be used to promote system-wide improvements. Among these, staff recommend:

1. REQUIRE STATES TO HAVE AN APPROVED SYSTEM OF QUALITY ASSURANCE.

The federal government should set minimum national requirements for each state to construct and implement a aggressive quality assurance program for these small enterprises. The federal requirement should be flexible enough to recognize individual state conditions. As the University of Minnesota's Center for Residential and Community Services Institute concluded in its 1991 study of state efforts to affect quality assurance: "such an approach to standards would in no way diminish the efforts of those states that have already developed programs or quality assurance and enchantment. On the' other hand such a requirement for state programs would serve as a significant catalyst ..."

2. ESTABLISH A NATIONAL INFORMATION EXCHANGE AND QUALITY ASSURANCE/ENHANCEMENT EFFORTS.

States and small business providers need quick and reliable access to models that work. A clearinghouse should be established to provide states with information about what works as well as a repository for information about the track records of providers and personnel.

3. REQUIRE STATES TO ESTABLISH MINIMUM EMPLOYEE TRAINING REQUIREMENTS.

In case after case of poor quality of care, or of abusive treatment examined by the subcommittee, providers employed under-trained staff. Indeed, training provided by providers was often chaotic and the bare minimum necessary under the contract to meet state requirements. Training and professionalism should be the hallmark of a provider program, not a minimum requirement for licensure. Here again, without specifically mandating the shape of a training program, the federal government should require that states establish base training requirements for service providers as a qualification for federal funding.

4. CREATE INCENTIVES FOR IMPROVED EMPLOYEE PAY AND BENEFITS.

The individuals charged to assist and supervise our most vulnerable citizens require pay and benefits commensurate with the difficult tasks our society asks of them. So long as states contract with providers who choose to maximize profits by underpaying staff, it will be difficult to encourage well-trained and loyal employees critical to providing quality care to mentally retarded or developmentally disabled persons.

5. DISCOURAGE OVER-RELIANCE ON ANY SINGLE PROVIDER.

State and local MR/DD housing and support programs require options. Efforts to rehabilitate poor-quality providers all too often come at the expense of clients. MR/DD housing and service programs that put clients first have the ability to move quickly to replace poor providers. Federal funds should be used to encourage state to build a broad-base of residential and service options, as well as competing and alternative providers. The best situation – and one that should be encouraged – seems to be described by a system of competing, small businesses.

6. IMPROVE STATE FINANCIAL AUDITING OF PROVIDERS.

As was shown in Massachusetts, effective state auditing will minimize the opportunity for financial abuse. However, to be effective, an effort must be made to better audit how individual clients fare under provider care. HCFA should undertake a survey on appropriate accounting methods to develop a model audit program for states receiving Medicaid support.